



NATIONAL SICKLE CELL DISEASE AWARENESS MONTH, 2020

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BY THE PRESIDENT OF THE UNITED STATES OF AMERICA

A PROCLAMATION

As our Nation recognizes National Sickle Cell Disease Awareness Month, we do so with an unwavering commitment to a future in which people with the condition live fully, without pain and impediments, and ultimately experience a cure. My Administration, through the Department of Health and Human Services (HHS), is leading unprecedented activity in research, medical education, and models of care in support of people with Sickle Cell Disease (SCD). A cure is within reach, the Food and Drug Administration (FDA) has approved new treatments and more are on the horizon, and several initiatives are underway to make better use of all available tools in the battle against this disease.

SCD is a chronic, debilitating, inherited condition that afflicts 100,000 Americans -- primarily African-Americans and Hispanic-Americans. One in 13 African-Americans and approximately one in 100 Hispanic-Americans carry the gene for this disease. Those individuals with two copies of the gene have blood cells that are sickle-shaped, instead of cylindrical, which causes a disruption in blood flow that can damage many organs, including the brain and kidneys. A person with SCD can begin experiencing the negative effects in early childhood, including pain, organ damage, and risk of stroke. Unfortunately, it is estimated that only one in four patients with SCD in America receive the care that they need.

My Administration puts action behind our words, which is why I signed into law the "Sickle Cell Disease and Other

Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018" (Public Law 115-327). The bill reauthorizes an SCD prevention and treatment program and authorizes initiatives for research, surveillance, prevention, and treatment of heritable blood disorders. HHS is leading the way to identify and address barriers to care for patients, and several organizations have joined in developing education and training programs to better equip healthcare providers to identify and treat this disease. HHS has also begun collaborating with States on new payment models that will enable children living with SCD to receive the care they need.

We have made exciting progress towards our goal of extending the lives of Americans with SCD by 10 years and finding a cure by 2029. In January 2020, HHS launched a new, one-of-a-kind Sickle Cell Disease Training and Mentoring Program (STAMP), to train primary care providers on the basics of SCD evaluation and management. This innovative program is the result of critical collaboration between the Office of Minority Health and the Health Resources and Services Administration. The FDA has approved two new drugs to help prevent the complications of SCD, is providing leadership to reduce barriers and hasten the development of new treatments, and has developed multi-media educational resources for patients and their families. The National Institutes of Health (NIH) has initiated an aggressive portfolio of research, education, and capacity building, including the "Cure Sickle Cell Initiative" to accelerate gene therapies to cure the disease. NIH reports that the most promising genetic-based curative therapies for SCD could be available in clinical trials in the very near future.

My Administration is leading on SCD advancements both in the United States and throughout the world. In May 2019, HHS

leaders convened a roundtable with African health ministers, international health leaders, and SCD experts to chart a course to save hundreds of thousands of children around the world. Through NIH, we will continue to support the Sickle Pan African Research Consortium, and other Public Private Partnerships to develop gene-based cures.

The United States is helping raise the profile of SCD as a public health priority, by drawing attention to the work underway to create meaningful programs that immediately improve patients' lives. My Administration is committed to advancing treatment, research, and quality-of-care to improve the lives of people with SCD -- and ultimately to deliver a cure to the world.

This month, we take a moment to recognize all Americans with SCD and celebrate our progress toward future treatments. Together, we will secure a healthier future for all Americans.

NOW, THEREFORE, I, DONALD J. TRUMP, President of the United States of America, by virtue of the authority vested in me by the Constitution and the laws of the United States do hereby proclaim September 2020 as National Sickle Cell Disease Awareness Month. I call upon all Americans to observe this month with appropriate programs and activities to eliminate a disease we have known about for more than a century and to work to improve the quality of life of those living with SCD.

IN WITNESS WHEREOF, I have hereunto set my hand this thirty-first day of August, in the year of our Lord two thousand twenty, and of the Independence of the United States of America the two hundred and forty-fifth.